

Chapter 1 How to Use this Document

Purpose of the Epidemiologic Profile

The purpose of the Epidemiologic Profile is to provide information on the Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome (HIV/AIDS) epidemic for use in the planning of activities to prevent the spread of HIV, for planning services to people infected with HIV and those diagnosed with AIDS, and to inform policies and programmatic developments, both at the state and local levels, as they pertain to HIV/AIDS prevention and treatment.

This chapter of the Epidemiologic Profile describes how to use this document. It includes an overview of the organization of the document, a description of what the Epidemiologic Profile can be used for, and a description of the data sources used and their limitations. A glossary of commonly used epidemiologic terms and acronyms can be found in the Appendix.

Organization of the Epidemiologic Profile: Four key questions

The Epidemiologic Profile is a required component of the Centers for Disease Control and Prevention (CDC) HIV Prevention Cooperative Agreement application, which the Massachusetts Department of Public Health - HIV/AIDS Bureau submits to the CDC on an annual basis. The CDC's guidelines for the Epidemiologic Profile recommend that the document respond to four key questions:

- 1- What are the socio-demographic characteristics of the population?
- 2- What is the impact of HIV/AIDS on the population?
- 3- Who is at risk for becoming infected with HIV?
- 4- What is the geographic distribution of HIV?

The FY '2001 Epidemiologic Profile is divided into two volumes. Volume 1 provides a general response to each of the four key questions. It includes an Executive Summary and chapters on the Socio-demographic Profile of Massachusetts and an Overview of HIV and AIDS in Massachusetts. The Executive Summary highlights the impact of the epidemic on the general Massachusetts population. Volume 2 provides detailed analyses for each of the following at-risk population groups: Women; Injection Drug Users; Men who have Sex with Men; Adolescents and Young Adults; Heterosexual Men and Women; Immigrants and Refugees; Communities of Color; Persons over age 50; Incarcerated Persons; and Homeless Persons. Volume 2 also provides a localities chapter with city/town specific data, and a chapter which briefly summarizes the literature on emerging populations and other groups of interest, as identified by the Epidemiologic Profile Advisory Group.

Guidelines for the Use of Information

HIV and AIDS case surveillance is the primary source of the data presented in this report. HIV and AIDS case surveillance data only represent people who have been diagnosed with HIV or AIDS and for whom a case report was submitted to the HIV/AIDS Surveillance Program of the Massachusetts Department of Public Health by a health care provider. Some people have tested positive, but have not yet seen a health care provider while others may be infected with HIV, but have yet to be tested. In order to provide a broad view of the epidemic and to understand more fully which populations are at greatest risk, a variety of data sources have been used in this document in addition to HIV and AIDS surveillance data. These data sets have unique strengths and limitations depending on whether the data are self reported by the infected individual, the comfort of individuals to report personal behaviors, the willingness of providers to ask about risk history, and the documentation of accurate information in the medical record. Interpretation of any information in this document should be made in the context of the particular data source from which the statistics were derived.

Below are some general guidelines for interpretation of the data contained in this document. (These were adapted with permission from the Texas Department of Health). The section that follows, titled "Description of Data Sources", provides answers to the questions posed below. Finally, a table is included which summarizes the strengths and weaknesses of each data source.

1. Understand what you are looking at

- What does the information cover?
- Does it represent HIV that never progressed to AIDS or AIDS cases?
- Do the numbers represent new cases or cumulative numbers?

2. Know the limitations of the information sources

- How complete are the data?
- Does the information represent the general population or just a select subgroup?

3. Don't over-interpret the information

- Increases or decreases in small numbers are magnified when calculated on a proportional basis.

4. Use the data

- Don't be scared off by the limitations of the data: use it.

5. Look for consistencies between different sources of information

- Results are more believable if they are supported by multiple sources.

6. Mode of Exposure and Risk Behaviors

- Don't confuse *mode of exposure* and *risk behavior* (See Glossary of commonly used epidemiologic terms in the Appendix).

7. Risk Behavior and HIV Prevalence

- Be careful about defining the *potential* for spread of disease versus the *presence of HIV* in that population. It takes both.

8. Case Reporting

- Are you looking at cases by *year of diagnosis* or *year of report*?

9. Measures

- Are you looking at a *rate*, a *count* or a *percentage*?
- Are you looking at *incidence* or *prevalence*?

Description of Data Sources

HIV/AIDS case surveillance is the primary source of data presented in this report, but it provides only a partial view of the HIV/AIDS epidemic. Other sources of data are also included to obtain a fuller picture of the current HIV/AIDS epidemic. Each data source presented in the report is described below.

AIDS Case Data: These data are collected by the MDPH Bureau of Communicable Disease Control HIV/AIDS Surveillance Program. AIDS has been a reportable condition in Massachusetts since 1983. Data are collected statewide from all licensed healthcare providers, who are required by law to report CDC-defined AIDS cases to the MDPH HIV/AIDS Surveillance Program. Reports received directly from health care providers (*passive AIDS surveillance*) account for the majority of AIDS cases reported in Massachusetts. The other method of AIDS case retrieval, *active surveillance*, relies on the use of case-finding tools such as database matches, death certificate reviews, and CD4 lab reports which lead to identifying cases otherwise not reported. This method accounts for a small but growing number of cases. Information collected includes gender, date of birth, country of birth, race/ethnicity, locality, and risk defined by category and assigned according to a hierarchy of what is thought to be the most likely source of infection when multiple potential sources are reported. Though the AIDS data are a dynamic data set which is continually updated, most cases are reported within 6 months of diagnosis; 2000 is the most recent year for which data are available.

Census Data: These data are collected by the US Census Bureau. Information is collected from each US state and territory, which includes gender, race/ethnicity, age, education and earnings, insurance, employment and housing. Data from the most recent (2000) census are used when available, otherwise data are from the 1990 census where indicated.

HIV Case Data: These data are collected by the MDPH Bureau of Communicable Disease Control HIV/AIDS Surveillance Program. The implementation of a non-name based surveillance system for HIV reporting was initiated by the MDPH in January 1999. These data are submitted by licensed healthcare providers who are required to report HIV cases to the MDPH HIV/AIDS Surveillance Program. Information collected includes gender, date of birth, country of birth, race/ethnicity, locality, and risk defined by category and assigned according to a hierarchy of what is thought to be the most likely source of infection when multiple potential sources are reported. Though the HIV data are a dynamic data set which is continually updated, most cases are reported within 6 months of diagnosis; 2000 is the most recent year for which data are available. The system is being evaluated as a model for surveillance not using personal identifiers. Preliminary evidence suggests that the non-name system is working well with effective prevention of duplicate reports, good sensitivity and specificity, and completeness of data similar to name-based systems.

Family Planning Clients and HIV Risk Survey: These data are collected by the MDPH Health Bureau of Family and Community Health Office of Statistics and Evaluation and

HIV/AIDS Bureau. Data were collected via a survey in 1998 of women using MDPH-funded family planning services in Massachusetts and assessed the frequency and interrelationships of certain HIV risk factors. Information collected includes race/ethnicity, age, and HIV risk factors. The most current complete year for these data is 1998.

High School Drop Out Data: These data are collected by the Massachusetts Department of Education. Data are collected for public school students throughout Massachusetts. Information collected includes gender, race/ethnicity, and grade. The most current complete year for these data is 1998.

HIV Counseling and Testing Data: These data are collected by the MDPH HIV/AIDS Bureau from MDPH-funded HIV counseling and testing (C&T) sites in Massachusetts. Since these sites provide approximately 30% of all C&T activity in Massachusetts, analysis of these data cannot be generalized to the entire Commonwealth. Information collected includes race/ethnicity, CDC-defined risk, reason for visit (partner notification, prenatal, etc.), and behavioral data, including unprotected sex in the past 6 months, and injection drug related risks. The most current complete year for these data is 2000.

Massachusetts Behavioral Risk Factor Data (BRFSS): These data are collected by the MDPH Bureau of Health Statistics, Research and Evaluation. These data are collected through the BRFSS, a comprehensive self-report survey on a full range of health influencing behaviors to Massachusetts adults via a random digit dialing sampling methodology. In recent years approximately 3,000 interviews have been conducted, including an over-sampling of minority residents and residents of the largest cities in Massachusetts. Information collected includes gender, race/ethnicity, age, locality, and behavioral data including HIV related risks. The most current complete year for these data is 2000.

Massachusetts Youth Risk Behavior Data (YRBS): These data are collected by the Massachusetts Department of Education. Data are collected through the Massachusetts Youth Risk Behavior Survey (MYRBS), which is a subset of the national school-based Youth Risk Behavior Survey (YRBS). A probability sample of 9th through 12th grade students is selected from public schools through a 3-stage sampling process. The survey is conducted every two years. Information collected includes gender, race/ethnicity, age, grade, and behavioral data including HIV-related risk. The most current complete year for these data is 1999.

Needle Exchange Program Data: These data are collected by the MDPH HIV/AIDS Bureau. These data are collected from 4 MDPH-funded needle exchange programs in Massachusetts. Data are collected from clients at 3 points in time: upon new client registration, at each needle exchange, and at continuous 6-month follow-up. Information collected includes gender, race/ethnicity, age, sexual and behavioral HIV risk data. The most current complete year for these data is 2000.

Pediatric Spectrum of Disease (PSD) Data: These data are collected by the Pediatric Spectrum of Disease (PSD) study administered through the New England Regional

Newborn Screening Program, University of Massachusetts Medical School. This study has been supported by the Centers for Disease Control and Prevention, Division of HIV/AIDS Prevention, Epidemiology Branch since 1989. Data are collected from seven hospitals through medical record review by nurse data abstractors who work for the individual hospitals. The nurse assigns a patient code number to each case to ensure the anonymity of information collected and abstracts the data every six months onto standardized forms designed for this study by the CDC. All HIV-infected and known perinatally exposed children are enrolled at birth or when HIV in the child is diagnosed.

Sexually Transmitted Disease (STD) Case Data: These data are collected by the MDPH Division of STD Prevention of the Bureau of Communicable Disease Control. These data are collected statewide from health care providers, who are required by law to report nine STDs, including syphilis, gonorrhea, chlamydia, and chancroid. Collection bias exists for some STDs, such as chlamydia, where screening of asymptomatic persons is done much more frequently in women than in men. Also, the personal nature of STD data may affect providers' willingness to report. The STD Division has promoted laboratory reporting as an adjunct to provider reporting to diminish bias. STD data is included because it indicates a level of risky sexual behavior. Unprotected sex, especially in a context where HIV prevalence is substantial, raises the likelihood of becoming HIV infected. Information collected includes gender, age, race/ethnicity, locality, infectious agent and clinical characterization of the infection. The most current complete year for these data is 2000.

Substance Abuse Admission Data: These data are collected by the MDPH Bureau of Substance Abuse Services. Data are collected in every publicly funded treatment site in Massachusetts. While these data can be said to be representative of all those seeking treatment at publicly funded sites, they can not be generalized to all substance users seeking treatment or all substance users in Massachusetts. Information collected includes gender, race/ethnicity, age, primary drug used, needle use, education, employment, and homelessness. The most current complete year for the admissions data is 2000.

Teen Birth Data: These data are collected by the Massachusetts Registry of Vital Records and Statistics. Data are collected from all Massachusetts birth certificates. Information collected includes race/ethnicity of the mother, age of the mother, and other birth indicators. The most current complete year for these data is 1999.

Unlinked HIV Seroprevalence Data: These data are collected by the MDPH Bureau of Laboratory Sciences. Data are collected from three selected STD clinics located in urban areas of Massachusetts. HIV seroprevalence studies have been conducted by the MDPH since 1988. Information is collected in a way that preserves anonymity but allows analysis by gender, race/ethnicity, age group, and some co-infections. The most current complete year for these data is 2000.

Summary of Strengths and Limitations of Data Used in the Epidemiologic Profile

Source of Information	Description	Strengths	Limitations
AIDS Case Data	<ul style="list-style-type: none"> Collected by MDPH Bureau of Communicable Disease Control HIV/AIDS Surveillance Program Reportable condition since 1983 Reportable statewide All licensed healthcare providers are required by law to report 	<ul style="list-style-type: none"> Statewide reporting, population based Risk information is available Completeness of reporting is high Comparable with other states 	<ul style="list-style-type: none"> Under-reporting (10% -15%) hampers interpretation of AIDS case data Not all cases are reported at time of diagnosis (reporting lag)
Census Data	<ul style="list-style-type: none"> Collected by the US Census Bureau 	<ul style="list-style-type: none"> Collected nationwide 	<ul style="list-style-type: none"> Only updated in 10 year intervals
Family Planning Clients and HIV Risk Data	<ul style="list-style-type: none"> Collected by the MDPH Bureau of Family and Community Health, Office of Statistics and Evaluation and HIV/AIDS Bureau A survey in 1998, of women using MDPH-funded family planning services in Massachusetts, which assessed the frequency and interrelationships of certain HIV risk factors. 	<ul style="list-style-type: none"> The survey sample was representative of women using MDPH-funded family planning services. 	<ul style="list-style-type: none"> Users of MDPH-funded family planning services differ from Massachusetts women of childbearing age overall
High School Drop Out Rates	<ul style="list-style-type: none"> Collected by the Massachusetts Department of Education 	<ul style="list-style-type: none"> Collected statewide 	<ul style="list-style-type: none"> Data is collected for public school only

Source of Information	Description	Strengths	Limitations
HIV Counseling and Testing Data	<ul style="list-style-type: none"> Collected by MDPH HIV/AIDS Bureau Collected at all MDPH-funded counseling and testing (C&T) sites in Massachusetts 	<ul style="list-style-type: none"> Provides behavioral risk information 	<ul style="list-style-type: none"> Since these sites only see about 30% of all HIV counseling and testing activity in Massachusetts, analysis of these data cannot be generalized to the entire state The type of client utilizing a publicly-funded counseling and testing site may not be typical of people at risk for HIV across the Commonwealth
HIV Case Data	<ul style="list-style-type: none"> Collected by MDPH Bureau of Communicable Disease Control HIV/AIDS Surveillance Program Reportable condition since January, 1999 Reportable statewide All healthcare providers are required by law to report 	<ul style="list-style-type: none"> Statewide reporting, population based Risk information is available Comparable with other states Focus on alive cases presents a more current picture of the epidemic than AIDS data 	<ul style="list-style-type: none"> May be incomplete because many infected people may not have been tested, or may know their status but have not yet entered care Non-named data set has limitations regarding matches with other data sets and case follow-up Code is not comparable with most other states
Massachusetts Behavioral Risk Factor Surveillance System (BRFSS) Data	<ul style="list-style-type: none"> Collected by the Bureau of Health Statistics, Research and Evaluation A comprehensive self-report survey on a full range of health influencing behaviors of Massachusetts adults via a random digit dialing sampling methodology 	<ul style="list-style-type: none"> Provides a random sample of the population Provides confidentially collected, behavioral risk information 	<ul style="list-style-type: none"> Not all potential participants live in households with a phone Not all individuals with phones will agree to be interviewed Survey is long and requires extensive time to complete Surveys general population and does not necessarily capture those at high risk Survey available in limited number of languages (English & Spanish) Data are self reported and not verified by medical records

Source of Information	Description	Strengths	Limitations
Massachusetts Youth Risk Behavior Data (YRBS)	<ul style="list-style-type: none"> Collected by the Massachusetts Department of Education A probability sample of 9th through 12th grade students is selected from public schools through a 3-stage sampling process. This self report survey is conducted every two years. 	<ul style="list-style-type: none"> Since Massachusetts Youth Risk Behavior Survey (MYRBS) is a subset of the national school-based Youth Risk Behavior Survey (YRBS), Massachusetts data can be compared to national data 	<ul style="list-style-type: none"> Surveys only in-school youth. Out-of-school youth may be at higher risk for HIV Due to how schools are selected, may not be representative of a community
Needle Exchange Program Data	<ul style="list-style-type: none"> Collected by the MDPH HIV/AIDS Bureau Data are collected at time of contact with clients at 4 MDPH-funded needle exchange programs in Massachusetts 	<ul style="list-style-type: none"> Collects behavioral data on a hard to reach population 	<ul style="list-style-type: none"> Non-representative sample of IDUs
Pediatric Spectrum of Disease Data	<ul style="list-style-type: none"> Collected by the Pediatric Spectrum of Disease Project 	<ul style="list-style-type: none"> Longitudinal study continuous since 1989 One of 7 PSD study sites in nation Completeness of data 	<ul style="list-style-type: none"> Uninfected children of HIV-infected mothers may never be enrolled Reporting lag
Sexually Transmitted Disease (STD) Case Data	<ul style="list-style-type: none"> Collected by MDPH Bureau of Communicable Disease Control Division of STD Prevention All providers are required by law to report nine STDs, which includes syphilis, gonorrhea, chlamydia, and chancroid 	<ul style="list-style-type: none"> Statewide reporting, population based 	<ul style="list-style-type: none"> Risk information is not reported Willingness of provider reporting affected by the personal nature of STDs Reports are not received from those not seeking care Bias is introduced for some STDs, such as chlamydia, where screening of asymptomatic persons is done much more frequently in women than in men

Source of Information	Description	Strengths	Limitations
Substance Abuse Admission Data	<ul style="list-style-type: none"> Collected by MDPH Bureau of substance abuse services Information on Substance abuse treatment admissions is collected in every publicly funded treatment site 	<ul style="list-style-type: none"> Collected statewide 	<ul style="list-style-type: none"> While these data can be said to be representative of all those seeking treatment at publicly funded sites, they can not be generalized to all substance users seeking treatment or all substance users in Massachusetts
Teen Birth Data	<ul style="list-style-type: none"> Collected by the Registry of Vital Records and Statistics Data from birth certificates 	<ul style="list-style-type: none"> Collected statewide 	<ul style="list-style-type: none"> Report is filled out by provider
Unlinked HIV Seroprevalence Data	<ul style="list-style-type: none"> Collected by MDPH Bureau of Laboratory Sciences 	<ul style="list-style-type: none"> Gives a part of the demographic picture of HIV prevalence Stringent methodology 	<ul style="list-style-type: none"> Limited to time of testing Limited demographic information Limited to clinic or treatment populations Not representative of the general population